Patient Education and Counseling 94 (2014) 427–431

Contents lists available at ScienceDirect

Patient Education and Counseling

journal homepage: www.elsevier.com/locate/pateducou

Relatives' Perspective

Assessment of family history of colorectal cancer in primary care: Perceptions of first degree relatives of people with colorectal cancer

Emilie Cameron [a,b], Shiho Rose [a,b], Mariko Carey [a,b,*]

[a] Priority Research Centre for Health Behaviour, Faculty of Health, University of Newcastle, Callaghan, Australia
[b] Hunter Medical Research Institute, New Lambton Heights, Australia

ARTICLE INFO

Article history:
Received 26 July 2013
Received in revised form 6 November 2013
Accepted 30 November 2013

Keywords:
Colorectal cancer
Bowel cancer
Family history of cancer
Primary care
First degree relatives

ABSTRACT

Objective: First degree relatives (FDRs) of someone with colorectal cancer (CRC) are at increased risk of the disease. In this study we examine the factors associated with discussing family history of CRC with a health professional.

Methods: People with CRC, recruited through the population-based Victorian Cancer Registry in Australia, were asked to refer FDRs to the study. Eight hundred and nineteen FDRs completed a telephone interview.

Results: Thirty-six percent of FDRs recalled ever being asked about their family history of bowel cancer by a health professional. Factors associated with having this discussion were being aged 50–60 years, having a university education, being in the potentially high risk category, being very worried about getting bowel cancer and knowing that family history increases risk through discussions with family, friends or their own education.

Conclusion: Despite evidence that doctor endorsement is a key factor in the uptake of CRC screening, our study shows that the majority of FDRs do not recall being asked by a health professional about their family history.

Practice implications: There is a need to identify the most appropriate method to improve rates of health professional discussion of family history with relatives of CRC patients in order to improve screening rates.

1. Introduction

Colorectal cancer (CRC) is the fourth leading cause of cancer related death worldwide [1]. Australia has one of the highest incidence with 1 in 22 people developing the disease by the age of 75 [2]. Those diagnosed at an early stage have a 5 year survival rate of 90%, compared with 10% for those with advanced metastatic disease [3]. Despite this, less than 20% of CRCs in Australia are detected at the earliest stage of the disease [4].

The risk of developing CRC increases sharply over the age of 50 and among relatives of those with CRC [5]. Based on the number of affected relatives and the presence of high risk features, Australian guidelines classify first degree relatives (FDRs) as at average/slightly above average risk, moderate risk, and potentially high risk. Different screening regimens are recommended for those in each risk category. Despite their higher risk, our data indicate that adherence to screening recommendations is only 39% among FDRs of people with CRC [6].

Adherence to screening guidelines requires that FDRs are aware of their level of risk, and the corresponding screening recommendations. There is no systematic mechanism for providing information about CRC risk for family members of those diagnosed with the disease. Therefore, it often falls to general practitioners (GPs) to assess risk and provide screening recommendations as part of preventive care. Our recent data indicate that being asked by a health professional about their family history of CRC was a significant predictor of being screened in accordance to guidelines among FDRs [6]. However, there is limited evidence that this does not routinely occur in clinical practice. In a survey of community dwelling Australians aged over 50, 38% reported ever being asked about their family history of CRC by a health professional [7]. A study in North America of patients with CRC who had a first or second degree relative affected reported 59% having a family history documented [8]. An audit of medical records in a North American family practice found 55% recorded a family history of

* Corresponding author at: Priority Research Centre for Health Behaviour, School of Medicine & Public Health, W4, HMRI Building, University of Newcastle, Callaghan, NSW 2308, Australia. Tel.: +61 2 4042 0702; fax: +61 2 4042 0044.
E-mail address: mariko.carey@newcastle.edu.au (M. Carey).

0738-399
http://dx.doi.org/10.1016/j.pec.2013.11.014

cancer while only 8% recorded age of onset [9]. A similar study in a UK hospital involving patients diagnosed with CRC under age 60 found 54% of case notes referenced family history of cancer and 20% included the age of diagnosis of family members [10].

In this study we examine the factors that are associated with discussing family history of CRC with a health professional. Prior research has shown that a recent family cancer event is most commonly the motivator for a FDR to visit their GP [11,12], with level of education also predictive in influencing health maintenance visits [13].

The aim of the current project was to: (1) describe the proportion of FDRs who report discussing family history of CRC with a health professional; (2) how and when they became aware of family history as a risk factor; and (3) identify whether older age, female gender, country of birth, education, greater family risk status, worry about getting bowel cancer, or how became aware of increased risk is associated with greater likelihood of having discussed family risk with a health professionals.

2. Methods

2.1. Eligibility

FDRs of people with CRC were eligible to participate in the trial if they were: (1) aged 18 or older; (2) English speaking; (3) able to provide informed consent; and (4) did not have a prior diagnosis of CRC, advanced adenoma, familial adenomatous polyposis (FAP), or Crohn's disease, ulcerative colitis, or other inflammatory bowel disease.

2.2. Recruitment

Data for this study were collected between February 2010 and November 2012. CRC patients were identified by the cancer registry and invited to participate in the trial if they were over 18, within ten months of diagnosis, English speaking and able to provide informed consent and considered able to participate by their clinician [14]. Consenting patients completed a baseline computer-assisted telephone interview (CATI) which asked about: (1) family history of CRC, high risk related cancers, high risk genes and FAP; and (2) total number of living FDRs over the age of 18, and whether the research team could contact them to invite the FDRs to participate. Information collected from the CRC patients was used to classify the family risk status of their FDRs according to a modified version of the National Health and Medical Research Council's risk categories [15]:

Category 1. At or slightly above average risk: Index cases (ICs) with no first or second degree relatives diagnosed with bowel cancer and who were diagnosed themselves over age 55.
Category 2. Moderately increased risk: ICs diagnosed before the age of 55 without other high risk factors and those with 1 or 2 first or second degree relatives not on the same side of the family diagnosed with bowel cancer without any high risk features.
Category 3. Potentially high risk: ICs diagnosed under the age of 55 with multiple bowel cancer or 2 or more first or second degree relatives on the same side of the family diagnosed with bowel cancer, or a first or second degree relative with any high risk features. High risk features include multiple bowel cancers in one person; bowel cancer diagnosed before the age of 50; a relative with cancer of the endometrium, ovary, stomach, small bowel, renal pelvis, ureter, biliary tract or brain; a FDR with FAP; or a relative with a high risk gene identified through genetic testing.

FDRs that consented participated in a brief screening interview to assess trial eligibility. Those with a prior diagnosis of CRC, advanced adenoma or FAP, or Crohn's disease, ulcerative colitis, or other inflammatory bowel disease were considered ineligible.

2.3. Measures

Eligible FDRs completed a baseline CATI comprising a series of modules a subset of which are reported here.

Socio-demographic questions: Items included age, gender, country of birth, postcode, marital status, level of education, employment status and whether they have private health cover. The relationship between the FDR and the IC was known from the IC interview.

Awareness of family risk: FDRs were asked when they first became aware that having a family history of bowel cancer increases a person's risk of developing bowel cancer ("less than a month ago"; "1 month to less than 12 months ago"; "12 months to less than 2 years ago"; "2 years to less than 5 years ago, 5 years or longer"; "Don't know that family history increases risk"), and were asked what first alerted them to this fact ("The letter I received from the Cancer Council"; "A member of my family was diagnosed with bowel cancer"; "Information from the TV, radio or newspaper"; "My doctor discussed the risk of bowel cancer with me"; "Other"; "Don't know/Not sure").

Discussions with health professional: FDRs were asked whether a health professional had ever asked about their family history of bowel cancer, the type of health professional who asked ("GP", "cancer specialist", "genetic counsellor" or "other"), how long ago they were asked ("less than a month ago"; "1 month to less than 12 months ago"; "12 months to less than 2 years ago"; "2 years to less than 5 years ago, 5 years or longer"; "Don't know/ Not sure") and how many times they have consulted that health professional about family history or bowel cancer or screening for bowel cancer.

2.4. Data analysis

All analyses were conducted in Stata 11.2. Responses to the survey questions were tallied and divided by the total number of participants to calculate proportions, taking the response "Not sure" as a negative response. The characteristics of FDRs associated with having discussed their family history of CRC with a health professional were assessed using logistic regression modelling in a generalized estimation equation framework to account for multiple FDRs per family. The variables age, gender, Australian born, education, family risk category, level of worry and how they became aware that a family history increased risk were entered into the model. Those who knew that a family history increased risk due to discussions with a doctor were excluded from the regression analysis.

2.5. Ethical approval

This study was approved by the University of Newcastle (2008-0047) and Cancer Council Victoria (0810) ethics committee, and all participants provided written consent.

3. Results

Of the 2928 eligible ICs sent a letter by the registry, 1084 (37%) gave consent for their details to be given to the research team and 753 (69%) completed the baseline interview. Of these, 649 (86%) had FDRs and agreed to them being invited to participate in the study. This led to 2376 FDRs being sent an invitation letter and 904 (38%) consenting to complete the interview to assess trial

eligibility. Consenting FDRs were more likely to be female ($X^2(1) = 34.0$, $p < 0.001$) compared with FDRs who were sent the invitation letter but did not consent to the study. There was no difference in consent rate depending on family risk status and relationship to the IC (Carey et al., unpublished). Forty consenting FDRs were ineligible to participate and 819 completed the baseline interview. These FDRs belonged to 416 families with an average of 1.91 members (SD = 1.13) per family. The demographics of the FDR participants are shown in Table 1.

3.1. Discussions with health professional

Overall 36% (295/819) of participants recalled ever being asked about their family history of bowel cancer by a health professional. Most discussions about family history of bowel cancer were with a GP (84%) while 20% involved a cancer specialist, 1.4% a genetic counsellor and 4.4% another sort of medical professional. Most of the discussions took place in the past 12 months (69%). However, 16% were over 5 years ago. On average FDRs who have discussed family history with a health professional have done so on 2.34 occasions (SD = 2.18).

3.2. Awareness of family risk

Just under half the sample reported that they had known that family history increases risk of bowel cancer for longer than 5 years (46%) while 43% became aware in the past year. The length of time that participants knew this fact was dependent on how they knew (Table 2; $X^2(3df) = 308$, $p < 0.001$). Those who found out after a family member was diagnosed (62%) or from the letter sent by the Cancer Council (3%) were more likely to have found out recently compared to those who knew from information obtained from the media (18%), discussions with their doctor (3%), from their own education (10%) or talking with friends and relatives (4%).

Table 1
Characteristics of FDRs included in the study ($N = 819$).

	N (%)
Age, mean (SD)	51 years (14)
Under 40 years	168 (21%)
40–49	214 (26%)
50–59	215 (26%)
60–69	130 (16%)
Over 70 years	92 (11%)
Male	334 (41%)
Australian born	752 (92%)
Live in urban area	471 (58%)
Married/Defacto	636 (78%)
Education	
University degree	354 (43%)
Vocational training	177 (22%)
Completed high school	107 (13%)
Did not complete high school	181 (22%)
Employment	
Full or part time work	569 (74%)
Retired	138 (18%)
Not working	62 (8%)
Private health cover	576 (70%)
Family risk status	
At or slightly above average	443 (54%)
Moderately increased	131 (16%)
Potentially high	245 (30%)
Relationship to patient	
Parent	30 (3.7%)
Sibling	287 (35%)
Child	502 (61%)
Level of worry about getting bowel cancer	
Not at all worried	314 (38%)
Slightly worried	360 (44%)
Very worried	145 (18%)

The results of the multiple logistic regression modelling are presented in Table 3. The factors associated with being asked by a health professional about family history of bowel cancer are: aged 50–60 compared to under 50, having a university education, being in the potentially high risk category, being very worried about getting bowel cancer and knowing that family history increases risk through discussions with family, friends or their own education. Gender and whether participants were born in Australia did not influence whether a health professional had discussed family history.

4. Discussion and conclusion

4.1. Discussion

Despite having a FDR diagnosed with bowel cancer only 36% of participants reported being asked about family history of CRC by a health professional. These results are in line with a recent study by Courtney et al. [7] of community-dwelling adults aged 50 and older, which found that 38% had been asked about family history by a health professional. Previous research has shown that doctor endorsement is a key factor in promoting screening participation [12,16,17]. Therefore, the low rates of recall of doctor discussion identified in this study are of concern.

Those aged 50–60 were more likely than younger participants to have discussed family history with their doctor. This may reflect that current screening guidelines recommend population screening for CRC commence at age 50. Therefore, some participants in this age group should have been contacted by the National Bowel Cancer Screening Program and may have discussed the invitation with their doctor, or may have had their doctor proactively initiate discussion of CRC screening given that they are at the appropriate age for screening.

Those at highest risk of CRC were also more likely than other respondents to have had a discussion about family history. A study by Honda and Neugut [18] demonstrated that perceived risk may be a dose-response relationship, i.e., the greater number of family members affected, the greater the perceived risk. Therefore it is likely that those at highest risk who may have several relatives affected by CRC are more aware of their risk, and have potentially been exposed to triggers to discuss this with a health professional. As found in other studies [13] level of education was also associated with discussing family cancer history with a doctor.

Over half of the participants knew about increased risk associated with family history due to a family member being diagnosed with CRC. This is similar to the findings of Lim et al. [12] that family cancer events and reaching the age at which relatives were diagnosed with cancer had a bigger impact in raising the awareness of the risk due to family history than the media and publicity. This is likely due to the feelings of personal susceptibility that a family cancer event may evoke. Nevertheless, media campaigns have been shown to be effective in increasing awareness of and promoting uptake of health behaviours in relation to some screening behaviours [19,20], and hence, the potential role of the media in relation to awareness of the risks conferred by family history of CRC should be further explored.

4.1.1. Limitations

One of the strengths of the current study was the attempt to gain a population perspective by contacting all eligible ICs identified through a population-based cancer registry, and subsequently contacting the FDRs of consenting ICs. The consent rate for ICs and FDRs in the current study was low, however, raising concerns about generalizability of the results. While we were unable to collect data on these characteristics, it is possible that non-consenters were less health conscious and had lower health

Table 2
How long FDRs have known that family history of bowel cancer increases the risk of developing bowel cancer by how they know ($N = 804$).

	Know because a family member was diagnosed	Know through the media	Know through talking with doctor	Know through family or friends or own education	Total
	N (%)	*N* (%)	*N* (%)	*N* (%)	*N* (%)
Known for less than 2 years	371 (71%)	10 (7%)	7 (39%)	2 (2%)	390 (49%)
Known for longer than 2 years	153 (29%)	136 (93%)	11 (61%)	114 (98%)	414 (51%)
Total	524 (65%)	146 (18%)	18 (3%)	116 (14%)	804

literacy than participants. This may have led to an overestimation of the proportion who recalled discussing family history of CRC with their doctor.

It is possible that recall biases may have affected participants' ability to accurately recall the timing of discussions with health professionals. However, bounded recall techniques including cues such as diagnosis of a family member, or receipt of the letter from the Cancer Council about the study were used, and may have facilitated recall.

4.2. Conclusion

Our data indicate that despite the evidence that doctor endorsement is a key factor in the uptake of CRC screening, the majority of FDRs of people with CRC do not recall being asked by a health professional about their family history. While other studies have identified this as a potential gap, ours is the first to do so in a population-based sample of FDRs of people with CRC. This suggests that even those who are at higher risk of CRC (i.e. those with an FDR with CRC) are unlikely to recall having discussed this risk factor with a health professional. There is a need to identify the most appropriate method of providing FDRs information about potential risks of developing CRC that is tailored to their level of risk.

4.3. Practice implications

Given that there were many cases where discussion of family history did not occur following a family member's diagnosis, the development of systems to prompt initiation of this in primary care is warranted. Other approaches using the IC diagnosis as the catalyst for providing screening information to FDRs through cancer registries [14,21], and through cancer treatment centres [22] should be investigated. Despite influence of primary care physicians being commonly acknowledged as a strong indicator for screening behaviour, advice from surgeons and other cancer specialists may also be considered as an appropriate strategy to reach FDRs through patients and encourage consultation with their GP regarding CRC risk [23,24].

Results indicate that strategies designed to promote discussion of family risk and screening recommendations for CRC need to be appropriate in reaching subgroups who were less likely to recall having had such discussions in the past: those with less education, those who are less worried about developing CRC, and those with lower risk of CRC. For example, strategies may need to emphasise the need to discuss CRC risk even if you only have one affected relative, or alternatively GPs could adopt an opportunistic approach whereby screening recommendations are provided to

Table 3
Multiple logistic regression model of factors associated with having discussed family history of bowel cancer with a health professional ($N = 786$).

	Asked about family history	Odds ratio	*p* value
	N (%)	(95% CI)	
Age categories			
Under 40 years	**53 (32%)**	**0.56 (0.35–0.89)**	**0.013**
40–50 years	**68 (33%)**	**0.62 (0.41–0.94)**	**0.026**
50–60 years[a]	**89 (43%)**	Ref	Ref
60–70 years	**42 (34%)**	**0.68 (0.42–1.1)**	0.113
Over 70 years	**25 (30%)**	**0.6 (0.34–1.08)**	0.087
Gender			
Male[a]	114 (36%)	Ref	Ref
Female	163 (35%)	0.86 (0.63–1.17)	0.335
Australian born			
No[a]	25 (38%)	Ref	Ref
Yes	252 (35%)	0.91 (0.52–1.58)	0.736
Education			
University degree[a]	139 (41%)	**Ref**	**Ref**
Vocational training	54 (31%)	**0.62 (0.41–0.92)**	**0.019**
Completed high school	29 (28%)	**0.57 (0.35–0.93)**	**0.023**
Did not complete high school	55 (31%)	**0.66 (0.43–1.01)**	**0.057**
Family risk category			
At or above average risk[a]	137 (32%)	Ref	Ref
Moderately increased risk	44 (34%)	1.11 (0.7–1.75)	0.663
Potentially high risk	96 (41%)	1.55 (1.08–2.23)	**0.018**
Level of worry about getting bowel cancer			
Not at all worried[a]	95 (32%)	Ref	Ref
Slightly worried	123 (36%)	1.2 (0.85–1.7)	0.288
Very worried	59 (42%)	1.67 (1.07–2.6)	**0.025**
How know that family history increases risk			
Family member diagnosed	173 (33%)	Ref	Ref
Media	48 (33%)	0.98 (0.66–1.46)	0.927
Family, friends or own education	56 (48%)	1.76 (1.15–2.71)	**0.009**
Total	277 (35%)		

[a] Reference category.

all appropriate patients [25]. However, messages designed to increase perceptions of vulnerability also need to include information about the potential to reduce risk through screening participation and need to be presented in a way that is accessible and easy to understand for a broad demographic [26,27].

Conflict of interest

The authors declare no conflicts of interest.

Acknowledgements

This research was supported by a National Health and Medical Research Council grant (Grant ID 510776), a Strategic Research Partnership Grant from Cancer Council NSW to the Newcastle Cancer Control Collaborative (New-3C), and infrastructure funding from the Hunter Medical Research Institute. Sincere thanks to registry staff and research participants.

References

[1] Ferlay J, Shin HR, Bray F, Forman D, Mathers C, Parkin DM. Estimates of worldwide burden of cancer in 2008: GLOBOCAN 2008. Int J Cancer 2010;127:2893–917.
[2] Australian Institute of Health and Welfare. Australian cancer incidence & mortality (ACIM) books: bowel cancer for Australia. Canberra: AIHW; 2010.
[3] National Cancer Intelligence Network. Colorectal cancer survival by stage – NCIN data briefing. London: NCIN; 2009.
[4] Ananda S, McLaughlin S, Chen F, Hayes I, Hunter A, Skinner I, et al. Initital impact of Australia's National Bowel Cancer Screening Program. Med J Aust 2009;191:378–81.
[5] Fuchs CS, Giovannucci EL, Colditz GA, Hunter DJ, Speizer FE, Willett WC. A prospective study of family history and the risk of colorectal cancer. N Engl J Med 1994;331:74–1669.
[6] Courtney RJ, Paul CL, Carey ML, Sanson-Fisher RW, Macrae FA, D'Este C, et al. A population-based cross-sectional study of colorectal cancer screening practices of first-degree relatives of colorectal cancer patients. BMC Cancer 2013;13:13.
[7] Courtney RJ, Paul CL, Sanson-Fisher RW, Macrae FA, Carey ML, Attia J, et al. Colorectal cancer risk assessment and screening recommendation: a community survey of healthcare providers' practice from a patient perspective. BMC Fam Pract 2012;13:17.
[8] Grover S, Stoffel EM, Bussone L, Tschoegl E, Syngal S. Physician assessment of family cancer history and referral for genetic evaluation in colorectal cancer patients. Clin Gastroenterol Hepatol 2004;2:813–9.
[9] Sifri RD, Wender R, Paynter N. Cancer risk assessment from family history: gaps in primary care practice. J Fam Pract 2002;51:856.
[10] Satheshkumar T, Saklani AP, Nagbhushan JS, Delicata RJ. Documenting family history in colorectal cancer patients – a retrospective audit. J Surg 2004;2:22.
[11] Al-Habsi H, Lim JN, Chu CE, Hewison J. Factors influencing the referrals in primary care of asymptomatic patients with a family history of cancer. Genet Med 2008;10:751–7.
[12] Lim JN, Hewison J, Chu CE, Al-Habsi H. Factors influencing consultation to discuss family history of cancer by asymptomatic patients in primary care. J Community Genet 2011;2:19–26.
[13] Jacobs LA. Health beliefs of first-degree relatives of individuals with colorectal cancer and participation in health maintenance visits: a population-based survey. Cancer Nurs 2002;25:251–65.
[14] Carey M, Sanson-Fisher R, Macrae F, Hill D, D'Este C, Paul C, et al. Improving adherence to surveillance and screening recommendations for people with colorectal cancer and their first degree relatives: a randomized controlled trial. BMC Cancer 2012;12:62.
[15] Australian Cancer Network Colorectal Cancer Guidelines Revision Committee. Guidelines for the prevention, early detection and management of colorectal cancer. Sydney: The Cancer Council Australia and Australian Cancer Network; 2005.
[16] McLachlan SA, Clements A, Austoker J. Patients' experiences and reported barriers to colonoscopy in the screening context—a systematic review of the literature. Patient Educ Couns 2012;86:137–46.
[17] Cole SR, Young GP, Byrne D, Guy JR, Morcom J. Participation in screening for colorectal cancer based on a faecal occult blood test is improved by endorsement by the primary care practitioner. J Med Screen 2002;9:147–52.
[18] Honda K, Neugut AI. Associations between perceived cancer risk and established risk factors in a national community sample. Cancer Detect Prev 2004;28:1–7.
[19] Grilli R, Ramsay C, Minozzi S. Mass media interventions: effects on health services utilisation. Cochrane Database Syst Rev 2002;1.
[20] Wakefield MA, Loken B, Hornik RC. Use of mass media campaigns to change health behaviour. Lancet 2010;376:71–1261.
[21] Glanz K, Steffen AD, Taglialatela LA. Effects of colon cancer risk counseling for first-degree relatives. Cancer Epidemiol Biomarkers Prev 2007;16:91–1485.
[22] Bampton PA, Sandford JJ, Young GP. Applying evidence-based guidelines improves use of colonoscopy resources in patients with a moderate risk of colorectal neoplasia. Med J Aust 2002;176:155–7.
[23] Madlensky L, Esplen MJ, Gallinger S, McLaughlin JR, Goel V. Relatives of colorectal cancer patients: factors associated with screening behavior. Am J Prev Med 2003;25:187–94.
[24] Zon RT, Goss E, Vogel VG, Chlebowski RT, Jatoi I, Robson ME, et al. American Society of Clinical Oncology policy statement: the role of the oncologist in cancer prevention and risk assessment. J Clin Oncol 2009;27:986–93.
[25] Sarfaty M, Wender R. How to increase colorectal cancer screening rates in practice. CA Cancer J Clin 2007;57:354–66.
[26] Davis TC, Dolan NC, Ferreira MR, Tomori C, Green KW, Sipler AM, et al. The role of inadequate health literacy skills in colorectal cancer screening. Cancer Invest 2001;19:193–200.
[27] Smith SK, Trevena L, Simpson JM, Barratt A, Nutbeam D, McCaffery KJ. A decision aid to support informed choices about bowel cancer screening among adults with low education: randomised controlled trial. Brit Med J 2010;341.